

Annual Program Performance Report

Employment, Transportation, Education & Early Intervention, Quality Assurance, Housing, Community Supports, Recreation, Childcare, Health, Partners in Policymaking, Mentoring, Collaborative Teaching, Transportation Solutions, College of Direct Support, DD Resource Center, People First, Self-Direction, Quality of Life, Family-to-Family, Advocacy, Change is Good, Youth Leadership,

ship, Public Policy, Voting, Legislation, Planning, Community Inclusion



*Missouri Planning Council For
Developmental Disabilities*



2007





Missouri Planning Council for
Developmental Disabilities

The Missouri Planning Council for Developmental Disabilities is a federally-funded, 23-member Council, appointed by the Governor. It is funded through the Administration on Developmental Disabilities under PL. 106-402. The Council's mandate is to plan, advocate for, and give advice concerning programs and services for persons with developmental disabilities that will increase their opportunities for independence, productivity and integration into communities.

The Council's mission is:

"To assist the community to include all people with developmental disabilities in every aspect of life."

The Council believes that mission will be achieved when people with developmental disabilities:

- make informed choices about where they live, work, play and worship;
- receive individual and family supports which are flexible, based on need, and provided in a culturally-sensitive manner;
- have the opportunity to engage in productive employment and meaningful retirement;
- experience continued growth toward their full potential;
- live in homes with the availability of individualized supports;
- are treated with dignity and respect;
- attend school with their peers in regular classrooms in neighborhood schools, and
- are members of powerful advocacy networks made up of individuals, parents and family members.

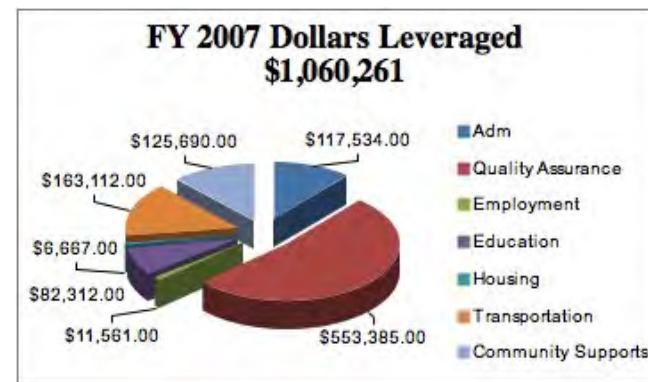
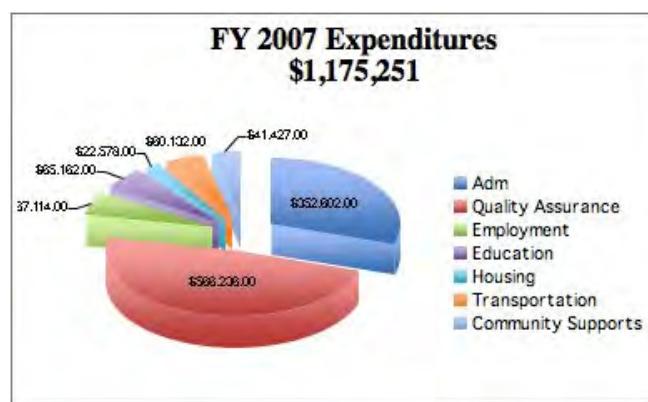
The Council also believes that individuals, parents and family members are the most powerful forces in forging a responsive and flexible support network for people with developmental disabilities.

The Council carries out its responsibility for **advocacy** under the DD Assistance and Bill of Rights Act by serving as an advocate for individuals with developmental disabilities and conducting or supporting programs, projects and activities that educate, advise and inform policy makers.

The Council engages in **capacity building** through its projects and activities that result in long-

term sustainable benefits for people with developmental disabilities. The Council does not provide direct services but focuses its efforts on bringing best practices to Missouri that will lead to increased community capacity.

We know that we have achieved **Systems Change** when we see sustainable, transferable and replicable change in some aspect of services or support availability, design or delivery that leads to positive or meaningful outcomes for people.



Developmental Disabilities are physical or mental impairments that begin before age 22 and alter or substantially inhibit a person's capacity to engage in the everyday activities of life, including self-care; communication; learning; mobility, or being able to work or live independently. Developmental disabilities may include Down Syndrome, Cerebral Palsy, Autism, Mental Retardation and others.

Over 100,000 Missourians experience developmental disabilities. This group of individuals is as varied as any other group of people. They go to school or work, have families and friends, nurture hopes and dreams and have expectations and potential.

State Plan Goals & Objectives

The Council is mandated to engage in planning, advocacy and capacity-building efforts contributing to persons with developmental disabilities leading more self-determined, inclusive and productive lives in their community. The Council developed a five-year plan to focus their efforts and establish priorities in some of the federal areas of emphasis identified by its funding organization, the Administration on Developmental Disabilities. The ADD areas include: Employment, education, housing, transportation, health, childcare, quality assurance, formal and informal community supports and recreation. The Council endeavors to reach their goals by releasing grants or "Calls for Investment (CFIs)". CFIs allow the Council to invest in short-term, competitive projects that identify and bring research-based, effective practices to Missouri to bring about systems change for Missourians with developmental disabilities.

Some of the Council's current goals and project investments include:

Employment: Individuals have the opportunity to be successful in obtaining and maintaining integrated competitive employment.



When applying for a job, this applicant found something totally unexpected... An employer who saw the value in him.

The Missouri Planning Council supported a project to develop a training program for state agencies to assist in increasing their potential for hiring and retaining individuals with developmental disabilities. The early pilot trainings were very well received and state Human Resource Directors asked if the council would transform the curricula into an electronic version. The final product will be released and made available to not only state agency human resource offices, but also to private businesses or small companies. The program is aimed at helping both the employer and co-workers feel more

comfortable and confident in their relationships with people with developmental disabilities. It will also assist employers and co-workers have a better understanding of the value of each individual's potential contribution and how to provide the limited supports necessary.

Education: Students and young children receive quality education in inclusive settings affording them the opportunities for transition to further their education or enter integrated employment opportunities of their choice.



Integration of people with disabilities into society must begin in public schools... That's elementary.

MPC awarded second-year funding to Clayton and Kirksville R-III School Districts to implement collaborative teaching methods district-wide. While professional development opportunities are available, there are few opportunities available that provide long-term support and technical assistance to

ensure that implementation of such training occurs and is embedded in the school culture. As a result of the commitment of the schools,

"The collaborative teaching project has kindled a renewed interest in collaborations of all kinds and provided the support to nurture that interest with professional development. While our focus this year has been on special education and general education teams, other teachers and specialists have not only attended training sessions, but also expressed a desire to explore this educational service method."

-- Carolyn Deffenbaugh, Clayton School District

more than 210 teachers have participated in professional development opportunities that have focused on inclusive education practices. The teachers have also had the support of consultants to ensure success of these methods in the classroom setting. Because of the success of these two districts, the council will release another Call for Investment in 2009 in conjunction with a statewide inclusion summit scheduled for October 2008. The MPC will bring experts to the

Summit who will share effective practices from across the nation with teams of school leaders, parents and others who are interested in implementing inclusive practices in their districts.

A second project provided support for three community programs to build mentoring projects for high school Juniors and Seniors that would enhance the young people's efforts to obtain employment



*When children with disabilities go to public schools, something happens in the community ...
The individual with disabilities becomes a part of it.*

and other successful individuals in jobs that correlate with their interests. In addition, students participate in skills development that include interview

skills, developing resumes, budgeting and financing and other skills needed to keep employment. The mentoring opportunities have led to several students developing work plans to begin their own businesses in such areas as detailing cars, small motor repair and lawn care. When one program recognized transportation as a major barrier, they sought outside funding to teach students how to drive, resulting in 21 students obtaining drivers' licenses. All three grantees have made the commitment to sustain the programs when Council funds are no longer available.

Quality Assurance: People are free of abuse, neglect, exploitation and violation of their human rights. They

are self-determined and have opportunities for independence, productivity, and integration and inclusion in the community.

The Council provides leadership training for individuals with developmental disabilities and their families through its investment in **Partners in Policy-making**. We now have 264 graduates from this program and we are seeing these graduates demonstrate leadership by engaging in such activities as building a coalition to work towards community inclusion in the St. Louis area, working with state legislators to get legislation introduced to remove the words "Mental Retardation" from the name of the Division of Mental Retardation and Developmental Disabilities and implementing an annual Ability Awareness Day at the local public school. Partners have been active in the media and several have participated in a statewide disability awareness campaign for people with disabilities. Partners graduates continue to be appointed to statewide boards and volunteer their time to serve on different boards to help assure the rights of people with disabilities across the state.

Following Governor Matt Blunt's announcement of his intention to close Bellefontaine Habilitation Center in January 2005, the Council contracted with a well-known researcher, James Conroy, Center for Outcome Analysis of Havertown Pennsylvania, to study the well-being of individuals who transitioned from Bellefontaine. While Bellefontaine has not closed, the residential census has been reduced considerably. Dr. Conroy's findings clearly demonstrate those individuals who moved into community settings report a statistically better quality of life in nearly every comparison performed. In addition, Dr. Conroy compared the data from the Missouri study to that of several similar large-scale studies which heightened his confidence in the results of the Missouri research. The **Quality of Life Report** was shared with policy makers, professionals and families across the state to help others increase their understanding of the gains in quality of life possible through community opportunities.

The Council contracted with a professional writer to capture the stories of several individuals who successfully transitioned to the community. These stories were compiled into a booklet, "**Change is**

Good", with pictures to help families, policy makers and professionals see first-hand how many individuals who were thought to never be able to leave the institution could transition and are now enjoying life in the community.

The Missouri **College of Direct Support** is an on-line training curriculum based upon the national Community Support Skill Standards designed to build a high quality direct support workforce in Missouri to meet the needs of individuals with developmental disabilities. The Council partnered with others to work toward embedding this program into the state's certification requirements and core budget. Currently, there are 30 pilot agencies throughout the state, including the Department of Mental Health, that access the curriculum. There are over 1,150 learners enrolled that have completed over 19,000 lessons. A total of 97 workers have graduated, completing the 13 courses and passing the on-the-job assessment.

Prompted by under-representation of individuals with disabilities at the election polls and the (later over-turned) requirement for voter identification, the Council supported two regional projects to address **voting issues**. Through this effort, over 150 individuals with disabilities were contacted by telephone, 72 were provided information in public meetings and 1,800 received information by mail that encouraged them to vote in the November 2006 election and explained how individuals could obtain proper identification. Public Service Announcements were posted and an 800 number was hosted to answer questions. In addition, 23 people were registered to vote and six people were assisted with transportation.

The Missouri Planning Council invests in **People First of Missouri**

in order to continue building and increasing the self-advocacy movement in Missouri.

People First of Missouri has established itself as an organization that



represents many people with disabilities. People First has over 40 local chapters in the state representing hundreds of people. They are now recognized as a

"Before People First, I was content with living with my parents and working at a sheltered workshop. Now, I live on my own and I don't work at the workshop, thanks to People First. People First has taught me a lot about numerous things."

strong voice at many "tables" in Missouri, with members sitting on local and statewide

boards and commissions all over the state. People First publishes a quarterly newsletter; hosts a yearly self-advocacy training camp (this year approximately 300 self-advocates attended); brings a steering committee together quarterly that includes representatives from each chapter to share information; advocates, and works toward common goals.

The Council invests in the **Missouri Developmental Disabilities Resource Center (MODDRC)**, which provides information on over 500 disabilities and related topics to any Missourian free of charge. This information can be tailored to meet individual needs by relaying the needs to the Resource Specialist by e-mail, face-to-face or over the phone. Information can also be accessed by using the web site, which provides overviews of the disability topics, personal perspectives from

individuals with disabilities and/or family members, support group databases, on-line links and state and local resources. The web site connects to the different resources and services related to such topics as employment, advocacy, services, education and aging. In FY 2007, there were 850 requests for information from the DDRC.

"Please keep this service available as well as the warm hot line. I have received so much support. Thank you!"

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"I use the information to give to families. I am a First Steps Service Coordinator. Families love to get this helpful information."

MODDRC also provides peer support through the **Sharing Our Strengths (SOS)** program, which is recognized as Missouri's Parent-to-Parent program. SOS matches families, caregivers and family members with others who are able to share their experiences, resources, or simply connect them with someone who will listen and understand. MODDRC received 102 requests for peer support this fiscal year. MODDRC had 280 trained SOS mentors in the database.

The most recent addition to the MODDRC is the **Volunteer Network**. This network provides opportunities for parents, self-advocates, professionals or other interested individuals to “volunteer” their time to give back to the disability community. There are many ways to get involved that will not only benefit the volunteer, but also the many other people who are touched by disability. In FY 2007, the Volunteer Network had 396 volunteers who participated in a variety of volunteer activities.

The **Community Support Navigator** program serves as a model of statewide and local community collaboration of disability organizations as well as other community-focused programs. The Council partnered with the University of Missouri-Kansas City Institute for Human Development through a grant awarded by the Missouri Service Commission and local organizations who serve as host sites to make this program possible. In FY 2007, 103 volunteers were recruited and served a total of 1,274 hours. A total of 1,585 persons with disabilities and/or their family members received mentoring from the 10 **AmeriCorps** members.



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The Council hosted a **Family-to-Family Conference** “Are We There Yet? Destination: Inclusion” for families of children of any age with developmental disabilities, individuals with developmental disabilities and professionals in the disability field that provided a wide variety of educational sessions and gave participants opportunities to learn about advocacy, education, disaster preparedness and planning for the future. Participants not only gained a wealth of information, but had opportunities for rest and renewal. Over 190 people participated and we have seen many participants return home to use their learnings and new skills.

The **Missouri Youth Leadership Forum** is a unique career leadership training program for high school Juniors and Seniors with disabilities. Delegates participate in a four-day event that focuses on leadership cultivation, citizenship and social skills. This nationally-recognized program provides delegates with a

better understanding of leadership principles and their application; the disability experience and resources; assistive technology; developing and achieving career goals, and independent living and self-advocacy skills. Missouri now has graduated 65 delegates who continue to be appointed to statewide boards and volunteer their time to serve on different boards to help assure the rights of people with disabilities across the state.

Housing: *Individuals reside where and with whom they choose in non-segregated community settings with individualized supports.*

The Council believes that, in order for individuals to have access to homes of their own, they must be well informed about the options in their communities, their rights, and the resources developed to assist them with obtaining, modifying and maintaining a home. To provide increased housing opportunities for individuals with developmental disabilities, we have invested in a project that will result in a sustainable **central resource system** that can be easily navigated and will provide a **registry of affordable, accessible, integrated housing** in Missouri as well as resources to rent, buy or modify a home of one's own. We anticipate the availability of the resource directory in early 2010.

Health: *People are healthy and benefit from the full-range of needed health care services.*

As Missouri experiences cuts in Medicaid and subsequently redesigns its Medicaid program, the Council is concerned with the impacts that these changes have imposed on people with developmental disabilities and their families. The Council partnered with People First to publish a **Medicaid Reform booklet** that provided guidance for legislators regarding the impact that their decisions have on people with developmental disabilities. It included information about institutional bias, the importance of addressing the unique needs of individuals with developmental disabilities, the significance of durable medical equipment and the value of programs that allow individuals to work. Over 300 copies of this booklet were distributed to legislators, policy makers and other stakeholders. Many other organizations have used the points that council members made in their advocacy work.

Transportation: Transportation is available to individuals with disabilities that meet their needs.

The Council held a Transportation Sol-



*This woman has one thing holding her back . . .
The scarcity of accessible public transportation.*

utions Summit that brought information about effective transportation solutions from across the nation to communities interested in identifying their own transportation solutions. Participants were offered a chance to compete for three grant opportunities that supported a community to develop transportation solutions for their community. These two-year projects must develop sustainable projects that bring all community systems together to develop local solutions. We anticipate these projects will be ready

to share their outcomes in late 2009.

Cross Cutting: Legislators, policy makers and the general public have an increased understanding of the issues and needs critical to individuals with developmental disabilities and their families.

Council members were concerned that we were not effective in communicating the impacts that budget cuts and service declines have on individuals with disabilities and their families. We invested in a project to help us **develop a strong message** and then released a **public awareness campaign** that targeted specific audiences with precise messages. As with all public awareness campaigns, it is difficult to see immediate results, but the Council has been very pleased with the results that we can observe. We have received positive input from our State Department of Elementary and Secondary Education complementing our inclusion efforts. Many individuals and families have expressed appreciation for our willingness to tackle the really tough issues of institutionalization of people with developmental disabilities and we have had contacts from others wanting to partner with us to achieve common goals on transportation and employ-

ment. The project taught members and staff a great deal about communication and we now see this project as a beginning rather than a culmination of our effort. We approach communication in a more strategic manner and do a better job of investing in projects that not only focus on systems change but also look at how we will communicate the need for change and project outcomes with key stakeholders to bring about the change we desire.

The Administration on Developmental Disabilities mandates that the Council advocate for programs and services for persons with developmental disabili-



*Missouri spends over \$100,000,000 each year to keep people who have committed no crime locked away from society.
The real crime here is thinking that it's necessary.*

ties that will increase individuals' opportunities for independence, productivity and integration into communities. We meet

this mandate by participating in several advocacy efforts or projects. Some of these include:

- Establishing legislative priorities:
 - Medicaid: The Council worked to educate members of the General Assembly about the needs of people with developmental disabilities as they revamped the State's Medicaid program.
 - Voting Issues: The Council worked to oppose legislation that would require a photo identification be presented in order for an individual to cast a ballot in an election. This has the potential to limit access to the polls for people with disabilities.
 - Abuse and Neglect Issues: The Council tracked legislation and policy issues regarding abuse and neglect of individuals with developmental disabilities. The Council was instrumental in creating "One Missouri: A Coalition for Community Inclusion" to ensure every individual with developmental disabilities has the opportunity to live, work,

play and worship in the community of their choice.

- Medicaid Buy-In for Workers with Disabilities: The Council actively advocated for legislation to be passed that created the “Ticket to Work Health Assurance Program.” This program allows individuals with disabilities who work to buy-in to the Medicaid program in Missouri, thus allowing individuals to earn a living and continue to receive necessary health care and support. Advocates were successful in getting this legislation passed this session.
- TABOR (Tax Payer Bill of Rights): The Council continued to actively oppose “TABOR-like” legislation that would establish a state spending cap and use any surpluses to permanently reduce the state income tax.
- DD Act Reauthorization: The Council educated members and advocates about the importance of reauthorization and continues to advocate its passage.
- Working closely with People First of Missouri and other advocates around the state to get legislation filed and passed to take the words “mental retardation” out of the name of the Division of Mental Retardation and Developmental Disabilities: Although the legislation was not passed during the 2007 legislative session, Partners, self-advocates and supporters made significant progress in educating legislators regarding the issue and developed relationships with many State Senators and Representatives across the state.
- Providing leadership in the planning and recruiting of advocates to attend the 6th Annual Disability Rights Legislative Day. On this day, over 600 people attended a rally at the State Capitol and visited their legislators to speak about issues important to people with disabilities such as health care and funding for services.



“Let’s do some positive name dropping!”



- In order to orient new state legislators to issues that affect individuals with developmental disabilities and their families and the role of the Missouri Planning Council, council members and staff made coordinated visits to the offices of first-term legislators.

- Council members and staff also participated in numerous other organizations to advance the Council’s values and positions. Some of these include:

- *Arc of the United States Missouri Chapter*, a parent and self-advocate-driven organization that advocates on issues important to people with disabilities in Missouri. Their mission is to support and empower persons with developmental disabilities and their families through advocacy and education, expanding individual choices and promoting community inclusion.



- *One Missouri*, a Coalition for Community Inclusion that encourages policy makers to establish policies and supports so that all people with developmental disabilities can live in the community rather than segregated settings.

- *Congress on Disability Policy*, a group of state-wide disability-related organizations who develop and advance legislative public policy agendas and advocate for an enhanced quality of life for Missourians with disabilities and their families by identifying common values that drive shared policy positions.

- *American Association for Intellectual and Developmental Disabilities*, a professional association run by and for professionals who support people with intellectual and developmental disabilities.

- *Association for Persons in Supported Employment (APSE-MO)*, a membership organization formed to improve and expand integrated employment opportunities, services and outcomes for persons experiencing disabilities.



Missouri Planning Council For Developmental Disabilities

“Let People With Disabilities Live Real Lives!”

Council Membership

The Missouri Planning Council is a unique entity bringing together people with diverse perspectives who are appointed by the Governor. Membership includes:

- People with developmental disabilities and their family members,
- Representatives of state agencies and service providers, and
- Advocates and other interested citizens.

Current Members

Shelly Shetley, Kansas City (Self-Advocate)

Paula Bonney, Waynesville (Parent)

Stephanie Briscoe, Lathrop (Parent)

Wendy Dillender, Jefferson City

(Older Americans Act Agency Representative)

Cathy Enfield, Independence (Self-Advocate)

Vim Horn, Kansas City

(University Centers for Excellence in Developmental Disabilities Representative)

Owen Lunn, Nevada (Self-Advocate)

Terry Mackey, Mexico (Parent)

Vicki McCarrell, Boonville

(SB40 & Sheltered Workshop Representative)

Joann Noll, St. Louis (Parent)

Robert O'Dell, Conway (Self-Advocate)

Sharon Smith, St. Louis (Self-Advocate)

Kit Stahlberg, Fredericktown
(Self-Advocate)

Gary Stevens, Rolla (Self-Advocate)

Charlie Taylor, Jefferson City
(IDEA Agency Representative)

Ad Hoc Members:

Tec Chapman, Jefferson City

(MRDD Agency Representative)

Susan Eckles, St. Louis

(Protection & Advocacy Services Representative)

Vicki Fry, Jefferson City

(Title XIX-Medicaid Agency Representative)

John Harper, Jefferson City

(Vocational Rehabilitation Agency Representative)

Let Us Hear From You

The Missouri Planning Council for Developmental Disabilities is interested in the experiences of people across Missouri. In order to assist us in breaking down barriers to successful, integrated community living that allows people with disabilities to live the lives they choose, we must first know what these barriers are! The experiences of people with disabilities and their families drive the work that we do. If you have a particularly frustrating experience getting a job, housing, health care or transportation; or if you have an experience where the systems that are supposed to be there to support you or your family member create a barrier, we would like to hear about it. Please visit our web site at mpcdd.com and share your story on the "Give Us Your Input" section.



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*"Let People with Disabilities
Live Real Lives"*

The Council is mandated under P.L. 106-402, the Developmental Disabilities and Bill of Rights Act, and federally-funded through the Administration on Developmental Disabilities. This document can be made available in alternate formats, upon request.